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Ghanadzade, Mehdi; Waltz, Mitzi; Ragi, Tehnaz

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The intervention priorities of parents of children with autism spectrum disorders in Iran

Mehdi Ghanadzade[a], Mitzi Waltz[b,*], Tehnaz Ragi[c]

[a] Neda Autism Rehabilitation Education Centre (NAREC), Tehran, Iran
[b] Athena Institute, Vrije Universiteit (VU Amsterdam), Amsterdam, Netherlands
[c] LIFEAsia Community Empowerment, Mumbai, India

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ABSTRACT

When designing and implementing evidence-based programs for children with an autism spectrum disorder, the intervention priorities of parents are important criteria. Although studies in developed countries have explored parents' intervention priorities, there is a paucity of this kind of research in developing countries. This research explores the intervention priorities of 207 Iranian parents for their children with autism in Tehran, the capital of Iran. Participants with children between 2 to 21 years of age were asked to rate their intervention priorities from among 10 main categories. In addition, correlations between children's difficulties and parental intervention priorities were examined.

The results indicate that building social communication skills was the highest intervention priority for parents of Iranian children with autism, a contrast to typical current service provision in Iran. The results also substantiated that presence of social communication difficulties and challenging behaviors in children are typically correlated with parents' intervention priorities.

1. Introduction

The intervention priorities of parentsof children with an Autism Spectrum Disorder (ASD) are important: understanding these and incorporating them into treatment and support programs is likely to increase parental acceptance, participation and satisfaction, and these factors are likely to lead to better outcomes for children. However, the priorities of parents in developing and developed countries may differ. This research seeks to understand the treatment priorities of parents in Iran, and to compare these with parental priorities reported in similar studies completed in developed countries. A secondary aim is exploring whether there is a correlation between parents' intervention priorities and their child's ability level.

Autism Spectrum Disorders are neurodevelopmental disorders that can be diagnosed by documenting difficulties in social communication skills and the existence of repetitive and stereotypical behavior (American Psychiatric Association, 2013). The most recent research literature indicates that the prevalence of ASD is increasing in most countries (Hill, Zuckerman, & Fombonne, 2015; Pellicano, Dinsmore, & Charman, 2014). This increase in prevalence is not believed to reflect a rise in incidence, but is instead derived from increased awareness and availability of diagnostic services (Rice et al., 2012). In Iran, the first study about the prevalence of ASD reported a rate of 6.26 in 10,000 (Samadi, Mahmoodizadeh, & McConkey, 2012), but a more recent study indicates that prevalence has reached 95.2 in 10,000 (Samadi & McConkey, 2015).

Parents and professionals try hard to find more effective and evidence-based interventions for their children or clients with ASDs

* Corresponding author.
E-mail addresses: mghanadzade@gmail.com (M. Ghanadzade), m.m.waltz@vu.nl (M. Waltz), tehnazragi@yahoo.com (T. Ragi).

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(Guldberg et al., 2011; Hickerson, Finke, & Choi, 2014; Parsons, Lewis, & Ellins, 2009). One of the essential components of evidence-based practice is considering parents' priorities in designing and applying intervention or education programs for children with ASD (Melnyk, Gallagher-Ford, Long, & Fineout-Overholt, 2014). Therefore, when choosing effective intervention plans for children with ASD, the first step can be exploring and considering the intervention priorities of their parents (Guldberg et al., 2011).

In addition, the literature indicates that the core features of ASD in children can lead to behaviors that parents find challenging (Williams et al., 2012). These challenging behaviors can increase the level of anxiety and stress in parents of children with ASD in comparison to parents of children with other developmental disorders, and this may decrease parents' satisfaction with the effectiveness of intervention programs (Russell & McCloskey, 2016; Williams et al., 2012). This possibility is substantiated by research indicating that when parents are involved in the process of determining intervention goals for their children with ASD, the level of their anxiety and stress can decrease remarkably, and this can lead to increased satisfaction with the intervention programs used for their children (Bloch & Weinstein, 2009; Dunn, Cox, Foster, Mische-Lawson, & Tanquary, 2012; Guldberg et al., 2011).

Moreover, for professionals working with children with ASD, it can be vital to determine parents' intervention priorities (Lang, Regester, Rispoli, Pimentel, & Camargo, 2010), in order to select appropriate treatment goals (Bloch & Weinstein, 2009). If intervention plans for children are designed via reciprocal interaction between parents and professionals, this enhances both the effectiveness of those plans and parents' satisfaction (Petrina, Carter, & Stephenson, 2015). In fact, when professionals in developing countries want to move from traditional intervention approaches (i.e. only one-to-one sessions without parents' involvement) towards family-centered services that place parents as experts on their child's needs, they first need to explore the parents' intervention priorities and then consider these when designing and carrying out intervention programs (Dunn et al., 2012; Schaaf et al., 2015).

Most studies exploring intervention priorities or educational needs of parents of children with ASD have been done in developed or western countries. For instance, in research carried out by Spann, Kohler, and Soenksen (2003), 45 parents of children with ASD reported that social skills, communication skills, daily life skills and challenging behaviors were their intervention priorities. In another study done with 350 parents of children with ASD, improving social skills was reported as the highest priority (Whitaker, 2007). In addition, Pituch et al. (2011) explored intervention priorities for 90 parents of children with ASD, and reported that among ten determined skill domains, the parents selected social and communication skills as their first intervention priorities for their children. Schaaf et al. (2015) indicated that 32 parents of children with ASD in a qualitative study reported daily living, play skills and social skills as their highest priorities for intervention. Petrina et al. (2015) worked with 74 parents of "high-functioning" children with ASD aged 5–10 years, and reported that when given a choice of social skills, motor abilities, finding friends, academic skills and emotional behaviors as a focus, parents selected social skills as their first intervention priority and emotional behaviors as the second. In a study with 148 parents of children with ASD aged five to 15 years from three different eastern European countries, the parents reported social communication skills as their highest intervention priority (Preece et al., 2017). Finally, in recent research involving 3317 parents of children with ASD, participants indicated that social skills were the first priority for the parents (Lai & Weiss, 2017).

In spite of this existing research base, this area still needs more research, in comparison with other topics in ASD (Lang et al., 2010; Petrina et al., 2015), and especially in developing countries (Kelly et al., 2016; Samadi & McConkey, 2011). In developing countries, most studies about ASD focus on the prevalence or etiology of ASD. For instance, Kelly et al. (2016) reviewed articles published about ASD in several Middle East countries, and concluded that 56.6% were related to the etiology of ASD. In Iran, a developing country located in the Middle East, most articles about ASD published in recent years focus either on prevalence (e.g. Samadi & McConkey, 2015; Samadi, Mohammad, Ghanimi, & McConkey, 2016) or on specific intervention methods (e.g. Mohammadzaheri, Koegel, Rezaee, & Rafiee, 2014; Abshirini, Khafaie, Bahrani, Rayshahri, & Khafaie, 2016), reflecting a focus on the needs of professionals rather than families or people with ASD themselves. The few studies involving parents of children with ASD in Iran focus on support services that parents might need (e.g. McConkey & Samadi, 2013; Samadi, McConkey, & Bunting, 2014). A cross-cultural study done regarding parents of children with ASD in Iran reported that among their ten main needs, Iranian parents needed time to spend with their colleagues and friends, or to receive supportive services to decrease their concerns about the future (Ahmadi, Zalani, & Amrai, 2011). None of these studies focused on exploring parents' intervention priorities for their child, or comparing these priorities with the priorities reported in developed countries.

2. Method

2.1. Questionnaires

To meet the aims of this study, a questionnaire that had been developed and used in a similar study in developed countries (Pituch et al., 2011) was translated into Farsi after getting permission from the original developers. This questionnaire surveys 54 behaviors, which are classified into 10 main categories. These categories are Self-care (6 behaviors), Domestic Living (4 behaviors), Community Living (4 behaviors), Job (3 behaviors), Recreational (4 behaviors), Motor (5 behaviors), Social (6 behaviors), Communication (7 behaviors), Academic (5 behaviors), and Challenging Behaviors (10 behaviors). The original developers remarked that these 10 categories and 54 behaviors had been chosen with regards to a review of scientific literature in the field of ASD and consideration of international organization guidelines (see Pituch et al., 2011, for more information).

Following forward translation into Farsi, a backward translation of this questionnaire in English was sent to the developers to ensure that key concepts had not been altered. However, there was a need to ensure that the content was also culturally valid. The original questionnaire included 54 behaviors, but after discussion between the researchers and the original developers, one behavior (finding an appropriate boyfriend and girlfriend) was removed from the social category, because in Iranian culture it is not common

for individuals with disabilities to choose a girlfriend or boyfriend. Another behavior removed from the questionnaire belonged to the Motor category (use wheelchair), because the children whose parents participated in this study did not have severe motor disabilities and none of them used a wheelchair. Indeed, the majority of children with ASD do not have significant motor disabilities. In a similar study using the same questionnaire, this item was also removed from final analysis, because no one had chosen this item (Pituch et al., 2011). Therefore, 52 behaviors were included in the Farsi version of the questionnaire. Face validity was assessed with 10 parents of children with ASD, and the results returned a very high score (0.97). Content Validity Ratio (CVR) and Content Validity Index (CVI) were also evaluated by 10 autism specialists who had at least five years of clinical experience in working with children with ASD. The CVR was 0.8 to 1, and the CVI was 0.99. Both CVR and CVI were in the acceptable range (see Ghanadzade & Alimi, 2016, for more information).

The completed Farsi questionnaire was made available in printed form for any parent of a child or children with ASD who wanted to participate in this study (see *Participants* for additional details).

The questionnaire was written in simple, clear language, and has two main sections. In the first section, demographic information about the parents and about their children is collected. In the second section of the questionnaire, the parents were asked to rate 52 behaviors in the 10 categories. The second section is divided into two parts (Part A and Part B).

In Part A, the parents were asked to rate 52 behaviors regarding their child's abilities using a five-point scale: parents should rate a behavior as 0 if their child has the ability to do that behavior independently. In contrast, if the child was totally dependent on others to complete that behavior, it should be rated as 4. Part A is therefore called the "Ability" section, and it was filled out by parents based on their perspectives about their child's level of independence regarding behaviors mentioned in Part A. In the Part B, parents were asked to rate 52 behaviors regarding their priorities for receiving intervention services. The scaling system for this part was the same as in Part A: if a behavior was definitely not a priority for parents, they should rate it as 0. If the behavior has low, medium and high priority for parents, the rating should be 1, 2 and 3 respectively. A rating of 4 should be chosen if the behavior is the highest priority for parents, something for which parents have a strong desire to receive intervention services. Part B can therefore be called the "Priority" section.

2.2. Ethical issues

Parents were told about the questionnaire, and could choose to pick up and fill out a copy or not. An information sheet and consent form was attached to every questionnaire. Parents who wanted to participate received an information sheet about the purposes and procedure of this study. They also received a consent form to sign. There was no obligation to either participate in the study or to fill out the questionnaire, nor was there any financial or other incentive offered in return for participation.

The research was carried out through several private service centers rather than through a university, so there was no formal ethics committee from which to seek approval. However, the researchers at all times conformed to the British Educational Research Association's *Ethical Guidelines for Educational Research* (BERA, 2014) as regards informed consent and other study procedures. There was no risk of harm to any study participant, no vulnerable people were asked to fill out the questionnaire, no deception was involved, and care was taken to ensure that data was collected and securely stored with regards to ethical procedures. Secure storage for completed questionnaires was agreed with the managers of rehabilitation centers, and the first author personally retrieved the completed questionnaires from the centres. Once the consent forms had been seen, a number was assigned to each participant and the questionnaires were separated from the consent forms, ensuring that the data was anonymous. No one except the researchers could access the data during or after the project. Anonymous questionnaire data were imported to SPSS directly by the first author.

2.3. Participants

More than 300 written questionnaires were distributed to five different rehabilitation centers in Tehran. If a parent expressed interest in participating, he or she was asked to read the information sheet first, and if they agreed to participate in the research, to read and sign the consent form. Then they could go to the next pages, which included the questions of the main questionnaire.

The five rehabilitation centers where the questionnaire was available provide outpatient services to children with disabilities, including those with ASD. Services are available to children and young adults from 1 to 25 years of age, and currently services are based on one-to-one sessions that are 45 min in length. Services include speech and language therapy, occupational therapy, play therapy and so on. The children usually receive each service they are assessed as needing once or twice a week, based on a primary assessment done by the supervisor of each center.

Through the rehabilitation centers, the researchers sought participants who were the biological parents of children with ASD living in Tehran. All participants and children used Farsi, the most commonly used language in Iran. All of the children whose parents participated in the study had a confirmed diagnosis of ASD and had been receiving ASD intervention services for at least six months in one of the rehabilitation centers. For all centres, ASD diagnosis is performed at intake or confirmed, if the child has already been diagnosed, by the supervisor, who uses the Gilliam Autism Rating Scales (GARS) and Autism Diagnosis Observation Schedules, Second version (ADOS-2). Parents of children with any comorbid disorders (e.g. cerebral palsy, Down syndrome and so on) were excluded from the study population, in order to only elicit intervention priorities that were specific to children with ASD.

Over a period of 12 months, 220 questionnaires were returned by parents who matched these criteria. All 220 questionnaires were checked manually by two authors of this article, and 13 questionnaires found to be incomplete. Incomplete questionnaires were not considered when tabulating the results, so a total of 207 completed questionnaires were used.

2.4. Data analysis procedure

Data obtained from the 207 completed questionnaires were imported into SPSS for analysis. The demographic information (e.g. age and education level) of participants and background information about their children (e.g. intellectual ability, social communication behavior and so on) were derived from the demographic part of questionnaire and are further detailed below.

In addition, the mean ratings for parents' priorities in each of 52 behaviors in 10 main categories in the questionnaires were calculated. This calculation was done to determine which behaviors were the top ten priorities for the parents, and also to identify which category was their highest intervention priority. When the mean rate for a behavior was higher than that for all other behaviors, that behavior was considered as a high priority for the parents. The 10 behaviors that received the highest mean rates (close to or above 3) can be presumed to be the top ten priorities for the parents.

Although this questionnaire had been used in three different studies and its construct validity had been confirmed (Pituch, Green, Didden, Whittle et al., 2010; Pituch, Green, Didden, Lang et al., 2010; Pituch et al., 2011), when a questionnaire is used in research it is recommended to implement Factor Analysis (FA) to extract the underlying latent variables (Howitt & Cramer, 2011). This was done for both Part A and Part B. It is recommended that FA should be used instead of principle component analysis (Pallant, 2010).

Because of the sample size, there was a concern that FA for whole items in 10 main categories of this questionnaire might not produce meaningful results, because for this kind of factor analysis the number of respondents should be 10 times of number of questionnaire items (Nunnally, 1978; Tabachnick & Fidell, 2007). To follow this rule, a sample size of 520 (52*10) would have been needed instead of 207. Accordingly, we decided to use principle axis factoring for each category in Part A and Part B separately, because the number of items in each category would not exceed 10. Therefore, the number of participants for each category would be more than 10 times the number of items. Another reason for choosing this method is that this questionnaire has 10 different categories, and principle component analysis of whole items might indicate 10 components similar to ten categories, as our primary analysis indicated. Using FA in each of categories separately and in each part to extract latent variables was therefore undertaken, employing direct oblique rotation (delta = 0) and examination of scree plot to select only the factors whose eigenvalue was greater than 1, regarding Kaiser's criterion (Pallant, 2010).

In addition to Factor Analysis, to support the secondary aim of this study it was also proposed to identify whether there was a linear correlation between abilities and priorities. This would determine whether or not when the child has significant difficulties in a behavior, that behavior was reported as the parents' highest priority. Therefore, linear correlation was checked between abilities and priorities for all categories.

3. Results

3.1. Demographic information: Parents and their children

SPSS was used to conduct descriptive statistical analysis. The first section of the questionnaire concerned demographic data about the parents and their children. Because the demographic part of the questionnaire used a ratio and interval scale, frequency of responses was analyzed in SPSS to elicit demographic information (see Tables 1 and 2).

3.1.1. Demographic information regarding parents

As seen in Table 1, most parents who participated were the mother of a child or children with ASD (n = 172, 83%); a minority of respondents (17%) were fathers. The parents were divided into nine age groups. These groups begin from around 20 years of age to around 60 years of age. The majority of parents participating were in three of these six age groups. These groups were: age 26–30 years (n = 33, 15.9%), age 31–35 (n = 60, 29%), and age 36–40 (n = 52, 25.1%). The smallest number of participants (n = 2, 1%) were in the youngest group (i.e. under 21) and only 2.9% of them were over age 55.

Table 1
Demographic information for parents participating in the study.

Demographic information regarding participants		Number	Percentage
Parent gender	Female (mothers)	172	83%
(N = 207)	Male (fathers)	35	17%
Parental age group	Under 21	2	1%
(N = 207)	21–25	4	1.9%
	26–30	33	15.9%
	31–35	60	29%
	36–40	52	25.1%
	41–45	23	11.1%
	46–50	16	7.7%
	50–55	11	5.3%
	Above 55	6	2.9%
Parental educational background	University degree (undergraduate and/or postgraduate)	100	49%
(N = 207)	Secondary school diploma	86	41%
	Has not completed secondary school	21	10%

Table 2
Demographic information for children whose parents participated in this study.

Demographic information regarding children of participants		Number	Percentage
Child gender	Female	162	78.3%
(N = 207)	Male	45	21.7 %
Child age group	2–4	47	22.7%
(N = 207)	5–7	70	33.8 %
	8–10	31	14.9 %
	11–13	20	9.7 %
	14–16	19	9.2%
	17–21	20	9.7 %
Child's IQ level	Above average	8	3.9%
(N = 207)	Average	41	19.8%
	Below average	28	13.5%
	Mild intellectual disability	14	6.8%
	Moderate intellectual disability	46	22.2%
	Severe intellectual disability	53	25.6%
	Profound intellectual disability	17	8.2%
Child's level of speech and language skills	Speaks fluently	11	5.3%
(N = 207)	Can use single words or simple phrases	113	54.6%,
	Non- or pre-verbal	83	40%

Around half of the parents (n = 100, 49%) participating in this study had graduated from a university (including both undergraduate and postgraduate degrees). Of the remaining parents, 41% of them (n = 86) had earned a secondary school diploma and 10% of them (n = 21) had not completed secondary school.

3.1.2. Demographic information regarding children

As shown in Table 2, the ratio of female to male children was 1–4 among 207 participants in this study: 78.3% (n = 162) of them reported having a male child with ASD and 21.7 % (N = 45) of them reported having a female child with ASD. All participants in this study had only one child with ASD. The children were divided into six age groups. More than half (56.5%) of children with ASD whose parents participated in this study were under 8 years of age.

Although 5.3% (n = 11) of children were reported to be able to speak fluently, the great majority of children (almost 95%) had difficulties with social communication skills that affected speech. This reflects the significant difference between ASD clinical populations in Iran and in developed countries, which is related to diagnostic procedures and cultural issues in Iran. Our clinical experience indicates that high functioning children with ASD are usually not diagnosed precisely, and children who are verbally fluent are rarely brought to rehabilitation centers to receive services.

The questionnaire used in this study also asked participants to categorize their child with ASD into seven intellectual groups. When parents of children with ASD want to use rehabilitation services or special facilities (e.g. receiving financial support, using social facilities developed for children with special needs and so on) in Iran, they need to register with the Iranian Welfare Organization (IWO) and can then be referred to a professional team that includes a pediatric psychiatrist, speech and language therapist, clinical psychologist, occupational therapist and social worker. The team first confirms the diagnosis of ASD, and then assesses the child with psychometric tools. The parents then receive an identification card for their child on which the child's Intelligence Quotient (IQ) is printed. The participants in this study were asked to categorize their children in seven groups based on the IQ printed in their children's IWO identification cards. One of these groups was above average intellectual ability, within which 3.9% (n = 8) of children were classified, while 19.8% (n = 41) of children were reported to be in the average intellectual ability group and 13.5% (n = 28) were in the below average intellectual ability group. The mild intellectual disability group was used to characterize 6.8% (n = 14) of the children, whereas 22.2% (n = 46) of the children were placed in the moderate intellectual disability group, 25.6% (n = 53) of the children in the severe intellectual disability group, and 8.2% (n = 17) in the profound intellectual disability group.

3.2. Top ten intervention priorities

The results of data analysis indicate that the 10 behaviors which were most frequently reported by the parents in this study mostly related to the Communication category. In fact, the first two behaviors are "responding to questions" (Mean = 3.26, SD = 1.01) and "describing events" (Mean = 3.29, SD = 0.99). In addition to these behaviors, other communication skills reported as fifth, sixth and seventh priorities are "initiating conversations" (Mean = 3.4, SD = 1.13), "following verbal directions" (Mean = 3.02, SD = 1.21) and "asking for more information" (Mean = 3, SD = 1.19), respectively.

As shown in Table 3, the highest priorities expressed by parents belonged to the communication, social, self-care, academic and community living categories. In other words, for parents, the highest-priority behaviors did not relate to the challenging behavior category. Another significant point is that most of the top ten priorities (around 6 out of 10) were for social communication skills.

Table 3
Highest priorities reported by parents of children with ASD.

	Highest priority	M (SD)	Main Category
1	Responding to Questions	3.29 (1.01)	Communication
2	Describing Events	3.29 (0.99)	Communication
3	Personal Safety	3.22 (1.11)	Community living
4	Listening to Teachers	3.07 (1.07)	Academic
5	Initiating Conversations	3.04 (1.13)	Communication
6	Following Directions	3.02 (1.21)	Communication
7	Asking for information	3.00 (1.19)	Communication
8	Pedestrian Safety Skills	2.95 (1.20)	Community living
9	Toileting	2.81 (1.39)	Self – care
10	Seeks out Interaction with Others	2.81 (1.17)	Social

3.3. Factor analysis

The results of factor analysis for all main categories in both the Ability part and the Priority part of the questionnaires indicates that the loads of the factors are more than 0.40 for all factors extracted in this analysis. It also indicates that there is only one underlying factor for eight out of 10 categories in both the Priority and Ability parts. These single-factor categories are: self-care, social, communication, community living, domestic living, job, motor, and recreational (see Table 4 for more information).

In contrast, in both the Ability and Priority parts of the academic category, two different factors were reported. The load of the factors for all items in the academic category, either in part A or in part B, is on the first factor, except for the item called "Listening to Teacher," where the load is on the second factor in both parts. The reason behind this may be because this item is related to language comprehension skills as well as academic skills. In contrast, items such as reading and writing might be considered more as purely academic skills.

Moreover, the result of factor analysis for the last category (challenging behavior) found three different factors underlying the items of this category. Again, the load of the factors for eight out of ten behavioral items listed in this category is on the first factor. The factor load for "Eating Difficulties" is on the second factor for both the priority and ability parts. In addition, the factor load for "Hyperactivity" was illustrated to be on the third factor. It may be that eating difficulties and hyperactivity were considered by parents as separate difficulties, and not as challenging behaviors. Parents may not follow clinical values for defining challenging behaviors, or they might only count severe challenges, such as self-injury and aggression, as challenging behaviors.

3.4. Correlation between parent priorities and their children's abilities

Firstly, we examined scatter plots for each category to explore whether there is linear correlation between abilities and priorities. As mentioned earlier, *Ability* in this context refers to the child's level of independence regarding the behaviors listed in Part A of the questionnaire. *Priority* in this context refers to the behaviors listed in Part B of the questionnaire that parents ranked as the most important areas for their child to achieve independence in. If the existence of linear correlation in a category was determined from scatter plot examination, we calculated the correlation between abilities and priorities in that category. The results of correlation and regression between Ability and Priority parts for all 10 categories indicated that there was a very high correlation between abilities and priorities in the challenging behavior category ($r = 0.71$, $p < 0001$, $n = 207$). This means that if a child has challenging behaviors, this is very likely to be an intervention priority for their parents. The correlation between abilities and priorities for the communication ($r = 0.56$, $p < 0001$, $n = 207$), self-care ($r = 0.55$, $P < 0001$, $N = 207$) and motor ($r = 0.53$, $p < 0001$, $n = 207$) categories were in the acceptable rage. This kind of correlation for the domestic living category ($r = 0.27$, $p < 0001$, $n = 207$) and social category ($r = 0.25$, $p < 0001$, $n = 207$) was lower, but it could be meaningful, because our sample size exceeded 100 and in this situation correlations between 0.2 to 0.3 can be statistically significant (Pallant, 2010). Therefore, there is a positive linear correlation between children's abilities and their parents' intervention priorities for six categories.

In contrast, for the community living category ($r = 0.05$, $p = 0.46$, $n = 207$), job category ($r = 0.12$, $p = 0.8$, $n = 207$), recreational category ($r = 0.05$, $p = 0.40$, $n = 207$) and academic category ($r = 0.13$, $p = 0.54$, $n = 207$) there was not a meaningful linear correlation between the Ability and Priority parts.

4. Discussion

The first aim of this study was exploring parents' intervention priorities for Iranian children with ASD. As shown in Table 3, the top ten priorities were derived and reported. These priorities mostly came from the area of social communication skills. Six out of the top ten priorities, including the number one priority, are directly related to social communication skills. It is important to note that the highest priority reported in this study is social communication skills, and this matches the results of several studies done in developed countries (e.g. Lai & Weiss, 2017; Petrina et al., 2015; Pituch et al., 2011; Preece et al., 2017; Spann et al., 2003). This indicates the importance of social communication skills for parents, and the significance of implementation or development of intervention programs to enhance these skills. In fact, this study discovered that although there might be some differences between

Table 4
Results of Factor Analysis of questionnaire results to elicit underlying latent variables.

Domain	Item	Factor		
		1	2	3
Self – Care Priority	Washing oneself (e.g. bathing, drying, washing hands)	**0.88**		
	Caring for body (brushing hair, brushing teeth)	**0.88**		
	Dressing	**0.91**		
	Toileting	**0.85**		
	Feeding	**0.78**		
	Looking after his/her own health (e.g. nutrition, exercise)	**0.61**		
Self – Care Ability	Washing oneself (e.g. bathing, drying, washing hands)	**0.88**		
	Caring for body (brushing hair, brushing teeth)	**0.89**		
	Dressing	**0.88**		
	Toileting	**0.90**		
	Feeding	**0.77**		
	Looking after his/her own health (e.g. nutrition, exercise)	**0.79**		
Domestic Living Priority	Cooking (e.g., prepares snacks, simple meals)	**0.82**		
	Household chores (e.g., washes dishes, makes bed)	**0.89**		
	Outside chores (e.g., sweep, tend garden)	**0.90**		
	Shopping (e.g., groceries, clothing)	**0.79**		
Domestic Living Ability	Cooking (e.g., prepares snacks, simple meals)	**0.62**		
	Household chores (e.g., washes dishes, makes bed)	**0.88**		
	Outside chores (e.g., sweep, tend garden)	**0.89**		
	Shopping (e.g., groceries, clothing)	**0.79**		
Community Living Priority	Use community businesses (e.g., restaurants, cinema)	**0.81**		
	Use public transportation (e.g., bus, taxi)	**0.83**		
	Pedestrian safety skills	**0.87**		
	Personal safety (appropriately cautious of strangers)	**0.82**		
Community Living Ability	Use community businesses (e.g., restaurants, cinema)	**0.77**		
	Use public transportation (e.g., bus, taxi)	**0.76**		
	Pedestrian safety skills	**0.81**		
	Personal safety (appropriately cautious of strangers)	**0.82**		
Job Priority	Having a job skill that could lead to employment.	**0.96**		
	Work ethic (e.g., getting to work on time)	**0.98**		
	Social skills at work	**0.98**		
Job Ability	Having a job skill that could lead to employment.	**0.76**		
	Work ethic (e.g., getting to work on time)	**0.89**		
	Social skills at work	**0.88**		
Recreational Priority	Plays with toys	**0.83**		
	Plays with peers	**0.88**		
	Plays sports	**0.86**		
	Outdoor leisure (e.g., hiking, riding a bike)	**0.89**		
Recreational Ability	Plays with toys	**0.58**		
	Plays with peers	**0.84**		
	Plays sports	**0.78**		
	Outdoor leisure (e.g., hiking, riding a bike)	**0.72**		
Motor Priorities	Sitting upright/sitting in a chair	**0.84**		
	Lifting and carrying objects	**0.91**		
	Fine motor skills (e.g., picking up, grasping objects)	**0.83**		
	Walking	**0.82**		
Motor Ability	Sitting upright/sitting in a chair	**0.76**		
	Lifting and carrying objects	**0.86**		
	Fine motor skills (e.g., picking up, grasping objects)	**0.62**		
	Walking	**0.73**		
Social Priorities	Shows affection to caregivers	**0.66**		
	Seeks out interaction with others	**0.82**		
	Interacts appropriately with familiar people	**0.83**		
	Interacts appropriately with unfamiliar people/strangers	**0.78**		
	Makes friends	**0.73**		
Social Ability	Shows affection to caregivers	**0.59**		
	Seeks out interaction with others	**0.83**		
	Interacts appropriately with familiar people	**0.85**		
	Interacts appropriately with unfamiliar people/strangers	**0.89**		
	Makes friends	**0.74**		

(*continued on next page*)

Table 4 (*continued*)

Domain	Item	Factor		
		1	2	3
Communication Priority	Expresses wants and needs	**0.73**		
	Names objects	**0.75**		
	Asks for information when needed	**0.77**		
	Can describe events/feelings	**0.69**		
	Initiates conversations	**0.74**		
	Responds appropriately to questions	**0.70**		
	Follows directions	**0.55**		
Communication Ability	Expresses wants and needs	**0.75**		
	Names objects	**0.83**		
	Asks for information when needed	**0.75**		
	Can describe events/feelings	**0.74**		
	Initiates conversations	**0.83**		
	Responds appropriately to questions	**0.81**		
	Follows directions	**0.70**		
Academic Priority	Drawing/coloring	**0.61**	0.44	
	Listens to teacher	0.40	**0.80**	
	Reading	**0.93**	−0.24	
	Writing	**0.94**	−0.15	
	Arithmetic	**0.90**	−0.24	
Academic Ability	Drawing/coloring	**0.73**	0.43	
	Listens to teacher	0.50	**0.78**	
	Reading	**0.91**	−0.24	
	Writing	**0.92**	−0.27	
	Arithmetic	**0.88**	−0.27	
Behavior Priority	Eating Difficulties	0.36	**0.83**	−0.10
	Sleeping Difficulties	**0.62**	0.53	−0.19
	Tantrums	**0.79**	−0.03	0.18
	Physically Aggressive	**0.74**	−0.33	−0.01
	Self-injury	**0.81**	−0.24	−0.02
	Hyperactivity	0.43	0.04	**0.69**
	Lack of activity/Overly passive	**0.72**	−0.09	−0.52
	Obesity/Overeating	**0.58**	0.22	0.22
	Noncompliant	**0.68**	−0.26	−0.31
	Resists change/Insists on sameness	**0.68**	−0.09	0.28
Behavior skills	Eating Difficulties	0.36	**0.75**	−0.34
	Sleeping Difficulties	**0.57**	0.57	−0.11
	Tantrums	**0.68**	0.23	0.20
	Physically Aggressive	**0.81**	−0.12	−0.10
	Self-injury	**0.78**	−0.06	0.10
	Hyperactivity	0.32	0.11	**0.84**
	Lack of activity/Overly passive	**0.75**	−0.33	−0.32
	Obesity/Overeating	**0.70**	−0.13	0.01
	Noncompliant	**0.66**	−0.41	−0.14
	Resists change/Insists on sameness	**0.78**	−0.03	0.13

Note: Factor loads > 0.55 are in bold face.

parents' priorities in developing countries and developed countries, regardless of their location, parents of children with ASD are in agreement about the importance of social communication skills.

Comparing the results of this research with a study done using the same questionnaire and a similar research method in developed countries indicates where some of the differences may lie. In Pituch et al. (2011), some of parents' highest reported priorities were in the job and recreational categories, but no behaviors from those categories were reported as top ten priorities in our study. Also, two behaviors from the academic category and two behaviors from the community category were highly ranked in their study, but in our study only one behavior was highly ranked from those categories. In addition, 40% of the top ten priorities reported in the 2011 study were from the social communication skills category, but in our study this percentage increased to 60%. Therefore, this study may indicate that social communication skills are significantly more important for parents of Iranian children with ASD. Our sample included mostly "low functioning" children, and that is likely to be one of the reasons that communication was seen as the highest priority.

In addition, the child's ability to communicate appropriately when speaking with others or to communicate their needs could be more important for Iranian parents of children with ASD for cultural reasons. The parents might emphasize these skills to help their children to be more able and less isolated in a collectivist society, and in one in which information and awareness about ASD is lower than the developed countries. Ten years of clinical experience of the first author in working with children with ASD in Iran has confirmed that Iranian parents of children with ASD usually are concerned about their child's future, and what will happen with the child becomes an adult, when the parents might not have enough ability to help or to communicate on the behalf of their child.

Parents are usually aware that there are not clear instructions for helping adults with ASD in Iran, and so they worry about what could happen in adulthood if their child cannot speak or communicate appropriately. This important issue should be especially considered by Iranian policymakers, professionals, educators and clinicians working with individuals with ASD in Iran, to ensure that all children are supported to develop social communication skills to the best of their ability.

In spite of significant emphasis of parents on social communication skills, most of the traditional Iranian intervention programs for children with ASD, especially for the children under 8 years of age, focus more on pre-academic and academic skills (e.g. numbers, shapes, colors and so on) rather than social communication skills. In fact, these programs mostly try to prepare a child with ASD to be able to pass a standard mainstream school entrance exam which is held every year. If a child can pass this exam, he or she can be registered for a typical mainstream school, instead of a special school. Pre-academic and academic skills are heavily evaluated in that exam. In addition, Augmentative Alternative Communication (AAC) systems such as the Picture Exchange Communication System (PECS; Bondy & Frost, 2004) or Makaton (Walker, 1987) are rarely used by Iranian professionals for children with ASD (Mohammadi, Salmanian, & Akhondzadeh, 2011), and most parents do not have information about the effectiveness of these systems for enhancing social communication skills in their children. Professionals should be supported to use such alternative communication systems more frequently to support the parents' priority for enhancing social communication skills. This might help parents be less concerned about their child's future, because their children would have a reliable way to communicate with others or express their needs. In addition, ability to communicate one's needs usually results in a lower frequency of challenging behavior, making it more likely that the child (and later, the adult) can be fully included in family and community life and make use of services.

The second aim of this study was exploring how far parents' priorities and their children's difficulties are correlated. This study indicated that children's difficulties in social communication skills and their challenging behaviors are correlated with parents' priorities. In other words, when parents perceive that the child has a particular difficulty with social communication skills or the child shows specific challenging behaviors, their parents' priorities are more focused on finding an appropriate solution for that challenge or improving that difficulty in social communication skills. The highest correlation reported was for the challenging behavior category, and this might show the importance of implementing suitable behavioral intervention programs by professionals when a child with ASD engages in challenging behaviors.

Based on this finding, further research should be conducted to explore the efficacy of behavioral programs implemented for Iranian children with ASD, because in Iran there is no university degree in the field of behavioral therapy and there is a paucity of short training courses for ASD behavioral interventions. For instance, regarding Board Certified Behavioral Analysis (BCBA), there is no international training course for behavioral analysis in Iran, and so far no BCBA-certified clinicians. Of course, other methods for understanding and addressing challenging behavior also exist in developed countries, such as the S.T.A.R (Setting, Trigger, Action, Result) approach for dealing with challenging behaviors in people with severe learning disabilities (Clements & Zarkowska, 2013), but the same gap in training and use exists. Experienced professionals, and parents, often find ways to work well with children who have challenging behaviors, but may lack a systematic understanding of why certain approaches are effective. This can limit their ability to extend approaches to new situations or other children. In fact, currently most professionals in Iran who deal with challenging behaviors in individuals with ASD must base their decisions on knowledge obtained mainly from reading books and surfing the internet. This level of knowledge is likely to be inadequate, and further training courses in the field of managing challenging behaviors might be needed.

4.1. Limitations and recommendations

Although this study explored the highest intervention priorities that parents of Iranian children with ASD have for their children and it was confirmed that there is a correlation between parents' priorities and children' abilities related to core feature of ASD (e.g. social communication skills and challenging behavior), there were some limitations. For instance, because the sample mostly included parents of "low functioning" children with ASD (generally, those with intellectual disabilities), the final results might be only pertinent to that group of individuals. Also, a convenience sample was used, and participation was entirely voluntary. The priorities of parents who did not choose to take part might be quite different.

Another limitation may be related to the questionnaire format. Using a pen-and-paper questionnaire can lead to low questionnaire return rates. In this case, 300 questionnaires were sent out, but only 207 could be used for analysis. However, using an Internet-based questionnaire would have been more difficult, because access to the Internet and the ability to fill in an Internet-based questionnaire were not evenly distributed amongst all parents of children with ASD in the proposed sample. Implementing a different method of research for obtaining parents' priorities (e.g. semi-structured or open-ended interviews) might encourage more parents to take part in this kind of research. Open questions, whether in an interview or a questionnaire, might be especially helpful to elicit cultural differences among participants.

Presentation of 52 items for rating in two different parts (i.e. part A and Part B) was also a challenge for parents. The rehabilitation centers where the questionnaire was delivered reported to us that once some parents had seen the number of the items, they decided not to take part. A short format of this questionnaire might be developed to evaluate priorities, and this might be more easily used in clinical or educational settings for extracting priorities and implementing them in practice. Further research should be done to develop such a short questionnaire.

It is essential to repeat this study in other cities in Iran, because in some cities the language and culture is totally different from the capital (Tehran). Knowledge is entirely lacking about intervention priorities of parents of children with ASD who are not able to use rehabilitation services in Iran for reasons such as lack of financial support from the Iranian government or living too far from the cities in which there are rehabilitation centers, and for parents who do not seek help at all. Comparing parents' intervention priorities

regarding male and female individuals with ASD is another suggestion.

Qualitative research in the form of semi-structured or open-ended interviews with both parents and professionals would determine priorities with greater precision, and would shed additional light on correlations between those priorities and children's difficulties as well. Although the questionnaire was written in very accessible and simple language, interviews would also address the issue of reaching parents whose literacy level is very low.

Another suggestion for further study might be evaluating how the reported priorities are being implemented in Iranian educational or clinical settings. It might also be useful to speak with adults with ASD in Iran about what supports and services they found especially helpful and productive during their childhood.

5. Conclusions

Interventions aimed at improving social communication skills appear to be the highest priority for parents of children with ASD in Iran, as has been reported in several previous studies involving parents in developed countries. This information can be useful for professionals, researchers and policymakers as they develop, design, implement, and advocate for evidence-based practices and family center services. Moving from the traditional approach (i.e. one-to-one sessions without parents' involvement, with academic goals as a high priority) towards more effective and evidence-based practices probably needs parental involvement. Fostering this involvement can begin by gaining a better understanding of parents' intervention priorities for implementing helpful practices. More research in this area may need to be done in developing countries, because although research on prevalence of ASD in these countries is of interest, the next and most important step can be to respond to the needs indicated by prevalence statistics. This would include focusing on other activities that could improve the lives of children with ASD, such as support and training for parents, family center-based services, current evidence-based practices, addressing the paucity of intervention methods and so on. The results of such research can be used to enhance the quality and usefulness of ASD services.

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